

Background

People live authentically when they can be true to themselves. Citizenship refers to the person's rights and obligations, but also to his or her social identity as part of civil society. Losses associated with ageing and the reality of life in a care home might suggest authenticity and citizenship are under threat. Furthermore, both notions are contested. Through a collaborative pilot project, bringing together academics, artists and a care home community we interrogated these concepts. Using qualitative ethnographic methods (observation and interviews), we probed how authenticity and citizenship might be maintained or enhanced by an art intervention. We consider how authenticity and citizenship are demonstrated and what factors might contribute to their realization.

Method

A visual artist engaged by Helix Arts (an Arts Council England National Portfolio Organisation) interviewed and made film and sound recordings of his interactions with selected residents with a range of cognitive and physical impairments. The aim was to produce a piece of art which could be exhibited to the local and wider community and digitally on an online platform. Informed consent and access to participants was carefully negotiated. ML employed ethnographic methods of non-participant observation in the care home before observing the work of the artist and interviewing residents, relatives and care home staff about their experience with the artist and their thoughts on citizenship and authenticity. Over 19 days, she interviewed 14 residents, 8 relatives and 9 staff. The interviews were digitally recorded, transcribed, and analysed with the help of NVIVO software for qualitative data management. The constant comparative method of qualitative analysis was employed and the validity of the thematic findings established through regular team meetings.

Citizenship

Citizenship is perceived in different ways by residents. To some, it meant doing more than the ordinary and making a contribution: being a 'good' citizen and 'productive'. But this could be difficult for others.

I just like to help people. That's my way of being a citizen.....And I love to walk up that path, though, and go into the coffee room and have a bit of a chat. HAR10

ML Okay how would you define a citizen?

HAR14 Well I suppose someone who takes more interest in the normal life. ... Oh well yes I am part of it. Not a very big part or not a very... productive one I don't think.

Involvement in group activities can be an opportunity for participative citizenship.

I think when they do activities, as a group and she participates, I think that's her being able to be a citizen and have the opportunity to contribute something or be involved in something that's of a group nature..... she can maybe help one of her fellow residents so that gives her a bit of citizenship within this. HAF2

Observations in the home showed that residents support and help each other in different ways, and in spite of cognitive and hearing deficits, are able to use gestures, hand-holding and physical embraces to make up for these losses.

Effect of an artist in a care home

Working in the context of a busy care home, the artist had to be flexible in order to collect material for his visual art. This involved taking time to engage personally with individual residents to record accounts of their lives.

I never make, so the way that I work, I never know what I'm getting, I've no agenda, I'm totally open.

He was effective in building relationships with residents, and those who had difficulty communicating with fellow residents benefitted greatly from this interaction. However, some of these exchanges were difficult for the artist.

he was getting upset because he was frustrated ... that he couldn't remember what his job was [] ... and those fundamental things of who he is as a person ... he's losing them ... or he's lost them and he knows it

Nevertheless, the effect of this relationship was that researchers and staff observed this male resident become more engaged in the social activities in the home soon afterwards. Staff then went on to make more provision for male residents in the female-dominated care home.

Objectives

The aim of the Helix ArCH project was to explore the notions of authenticity and citizenship by asking the following questions:

- 1) to what extent and how do people living with dementia in care homes express their authentic voice and demonstrate their citizenship?
- 2) what are the factors that contribute to their realization? and
- 3) how would a particular type of art contribute to enhancing or maintaining authenticity and citizenship for residents in a care home?

Authentic life

A precondition to authentic life appeared to be having your basic needs met. When asked if it was easier to speak up for herself as an older person, the following resident felt she was entitled to it. And why?

HAR7 Because I am me... True to myself... I don't care what they think, because I'm sitting here, I'm going to have tea, I get all my washing done, what else do you want?

A sense of identity continues to matter in a care home, which is something that is recognised by care home staff:

..you might have someone in one room loves their make-up on, loves their jewellery on but someone next door, might never have had that and wouldn't want you to do that. HAS7

While some residents have a strong sense of their identity, others experience losses that they feel they cannot recover.

if they want me to change to be something I'm not I won't do it.... Cos me, is me. HAR11

Singing was a part of me when I was young. I sang solos too. I don't sing now. HAR1

A distinct element of being authentic was residents' openness in envisaging or confronting death.

She kept saying, "I just want injected." She just kept saying, "Can the doctor not inject me with something because I've lived too long? HARF3

I've always thought I would just jump in to the sea and they would just wash me away HAR12

Salience of 'place'

There was a strong message from the staff that residents should feel at 'home' in the care home, and that as staff, they were 'working in their home', not a 'workplace'.

While some residents were very content in the home, others were ambivalent or pined to be in their own home. The following resident compared his situation with those in the private residences at the boundary of the care home.

I'm not sure I need to be here instead of somewhere else [laugh] you know that sort of like thing, depends who you're with HAR2

I mean if I lived in one of those houses over there and I just became ill and died ... I'd be buried in the local churchyard or whatever [laughs]. That would be a sort of freedom [ML – freedom?] that I don't have here.....HAR2

At the same time, activity coordinators provide residents with opportunities to attend events outside the home, such as 'Singing for the Brain'.

They went out the first day we came and she said, on one of the days, she said, "I've been out today," and we thought she was just making it up. We said, "Been out?" B said, "How did you go out?" she said, "Well in a taxi of course." HARF3A

While the dementia unit is a secure unit and necessarily so, the effect of this can be seen in the following quote.

I think upstairs is more, they talk more I think upstairs. I've always found anyway [] on the dementia unit I think they're more 'together' cos they all sit in the lounge a lot more than what we do down here. HAS9

Provisional conclusions

- With the support of the care home, residents with dementia can and do continue to live authentic lives as citizens
- That older people with dementia are citizens in their own right needs to be acknowledged by wider society
- Art that actively engages residents and the public in an authentic way can make this happen